



family @ linkages

NEWSLETTER

A way to connect families of children and youth with special needs in Michigan
with information, education and support



Never Leave Children Alone in Parked Vehicles.



On average, 38 children die in hot cars each year from heat-related deaths after being trapped inside motor vehicles.

On a day when the temperature outside is 86 degrees, the temperature inside a car can quickly reach 135 or even 150 degrees!

Research shows that leaving the windows open a crack does little to reduce this oven effect.

National Highway Traffic Safety Administration Tips to Prevent Injury & Death

- ➔ Never leave infants or children alone in an unattended car, even if the windows are partially open or the air conditioner is on.
- ➔ Make sure all passengers have left the vehicle after it is parked.
- ➔ Do not let your children play in an unattended vehicle.
- ➔ Always lock vehicle doors and trunks and keep keys out of children's reach.
- ➔ If you are bringing your infant or child to daycare, and normally it's your spouse or partner who brings them, have your spouse or partner call you to make sure everything went according to plan.
- ➔ Ask your childcare provider to call you if your child does not show up for childcare.
- ➔ Put something you'll need like your cell phone, handbag, employee ID or brief case on the floor board in the back seat.
- ➔ Be sure to remove children from the vehicle during busy times, schedule changes, emergencies or shopping for the holidays.
- ➔ If you see a child alone in a hot vehicle, call the police.
- ➔ If a child is in distress due to heat, get them out as quickly as possible and call 911.
- ➔ Warning signs of heat illness may include: red, hot, and moist or dry skin, no sweating, a strong rapid pulse or a slow weak pulse, nausea or acting strangely. Cool the child fast and call 911.

For more information about preventing injury, death and keeping kids safe, visit www.safekids.org or contact Linda Scarpetta with Safe Kids Michigan at (517) 335-9518. To locate a coalition in your area, visit: <http://www.safekids.org/in-your-area/coalitions/list.html?state=MI&localstate=MI>.



► August is National Children's Vision and Learning Month



Vision Screenings: It's never Too Early!

It's never too early to have your child's vision screened. Children don't know whether they have visual difficulties so early screening helps identify children at risk for vision problems.

In the first year of life, an optometrist or ophthalmologist can provide a vision exam to ensure that the eyes are functioning properly and that visual development is on track. InfantSee™, a national program offered by the American Optometric Association, provides for one eye exam for an infant between birth and 12 months at no charge. Parents can locate participating InfantSee™ optometrists at www.aoa.org.

In Michigan, local health departments provide vision screenings beginning at 3 years of age and all screenings are at no cost to children or families. Preschoolers, ages 3-5 years, and school-age children, in grades 1,3,5,7 and 9,

receive screenings as mandated by the Public Health Code. These screenings are usually conducted in the preschool and school settings in conjunction with your local health department.

Did you know? It's the law in Michigan that children entering Kindergarten must have their vision screened prior to the first day of school! Parents can contact their local health department or an optometrist or ophthalmologist to schedule a vision screening or exam within six months of the start of school.

Remember! It's never too early to have your child's vision checked! Early intervention improves visual development for those who have trouble seeing.

Contact your local public health department or go to www.mihearingvision.com for more information on how to conserve children's vision.



Playing with baby!

You've heard over and over again how important it is to play with your baby. Play helps your baby develop all the skills he or she is supposed to have.

But as you are playing how do you know if your baby is able to do what is appropriate for his or her age? Don't babies develop at different rates? Do you really need to worry about all of this at such a young age?

The development of your baby is wonderful and ever changing. You shouldn't worry about your child's development, but don't wait to address it if you have any concerns. Be sure to talk to your doctor about a developmental screening if you have any concerns about what your child is able to do.

If the screening identifies areas of concern, your doctor will refer you to community resources for additional testing. *Early On*® is a resource for children aged zero through two years who have a delay or a disability. *Early On* will use more detailed tools to see if your child does have a delay, and then work with you to help your child grow and learn. Your doctor may suggest referrals to other community resources such as a speech or physical therapist.

Developmental screening is a quick, easy, and reliable way to understand more about your child's development and gives you the opportunity to sit back and enjoy each new stage, without worrying.

If you are a parent and would like more information on developmental screening, please visit www.cdc.gov/ncbddd/childdevelopment. If you would like more information about *Early On*, please visit www.1800earlyon.org.

If you are a physician, and would like more information on training opportunities to learn to implement developmental screening contact Tiffany Kostelec at kostelect@michigan.gov.



➤ August is Spinal Muscular Atrophy Awareness Month

Spinal muscular atrophy (SMA) is the most common inherited lethal disease in children. About 1 in 10,000 children are born with the disease. SMA affects nerve cells, called motor neurons, in the spinal cord. These neurons affect voluntary muscles, the ones a person can control. As neurons are lost, the muscles weaken. This can affect crawling, walking, sitting up, and head and neck control. Sometimes the muscles for swallowing and breathing are affected. SMA is progressive, meaning the symptoms get worse with time. SMA does not affect the senses or intellect.

SMA is grouped into categories based on how severe the symptoms are and when they begin. It affects infants, children, and adults. SMA type 1, or Werdnig-Hoffman disease, is the most severe. Babies with SMA type 1 may show signs as early as before birth to several months after birth. Signs of SMA type 1 are fewer and “floppy” movements and trouble with breathing and swallowing. Severe SMA often causes death by 2 to 3 years of age.

SMA is a genetic disease. A healthy person may be a carrier of a SMA disease gene and not know it. About 1 in 40 people are carriers of SMA. Healthy parents can be carriers of SMA and unknowingly pass the SMA disease gene to their children. A child who inherits two SMA disease genes, one from each parent, will have the disease.

If both parents carry the SMA disease gene, then each child will have a 25% chance of developing SMA.

Genetic testing is available for SMA. It involves a blood test that is sent to a lab to look for the SMA disease genes. This test may confirm a diagnosis in a person with symptoms. For family planning, couples can ask to be tested to see if they are carriers of SMA before they start their family. Genetic testing is often covered by health insurance. Please check with your health insurance provider to find out which genetics services are covered by your health plan.

About 600 researchers around the world are currently working on finding an effective treatment and cure for SMA.

RESOURCES FOR FAMILIES WITH SMA:

Children’s Special Health Care Services (CSHCS) can help with medical expenses of children with SMA. Call the Family Phone Line at 1-800-359-3722 for more information.

Families of SMA (FSMA) offers information and support to families. Visit their website at <http://fsma.org/>. Contact FSMA Michigan Chapter at Michigan@fsma.org

The SMA Foundation works to speed up the development of a treatment for SMA through research. Visit their website at <http://www.smafoundation.org/>.



The Michigan Division for Early Childhood (MiDEC) is your Michigan source for information, resources, and guidance related to young children with special needs and their families.

MiDEC is dedicated to promoting policies and evidence based practice to support families and enhance the optimal development of all children. MiDEC shall encourage and promote the professional growth and quality practice to support young children with exceptional needs and their families.

The MiDEC Board has identified three priority areas.

- 1. Awareness and outreach:** We want to make sure that everyone in our state who cares about the development and education of young children with special needs knows about Michigan DEC. We will be working on “spreading the word” about our organization’s mission, goals, and activities.
- 2. Family involvement:** Michigan DEC is an organization comprised of families, professionals, and community members who care about young children with special needs. We will be working on strengthening family involvement in our organization.
- 3. Policy and advocacy:** We want to make sure that our members understand implications of public policy and are prepared to advocate for young children with special needs.

Now is a great time to get involved with MiDEC. Being a member offers the opportunity to work with committed groups of parents, professionals and community members through our subcommittee work. Subcommittees focus on outreach, governmental relations, professional development, fundraising, and parent involvement.

For more information visit our webpage: www.michigandec.org or contact Lydia Moore at lydiasmoore@yahoo.com.



➔ August is National Immunization Awareness Month



The Michigan Department of Community Health (MDCH) is recognizing August as Immunization Awareness Month in order to remind families about the importance of immunizations. Vaccine-preventable diseases still exist. Infants are too young to be fully vaccinated, so they are not protected from these preventable diseases yet. That is why it is so important to protect your entire family through immunizations.

In Michigan, there has been a steady increase in whooping cough over the past 10 years. In 2010, 1,500 cases of whooping cough (also called pertussis) were reported to public health departments. In 2011, there was a decline of about 55 percent; however, there were still nearly 700 reported cases in the state. (Also, many cases are not reported at all.)

But these numbers cannot communicate the human cost of this disease. In May, the worst case scenario occurred in southeast Michigan with a pertussis-related infant death. There were some media reports about it and the family is reaching out to the community to educate everyone on this preventable tragedy. This is a sad reminder to all of us about the importance of making sure that everyone who is around infants is vaccinated against whooping cough.

Getting immunized is a lifelong process. Vaccinations begin soon after birth and continue throughout life. Children receive most of their vaccines during the first few years of life. Other immunizations are recommended during the teen and adult years and, for certain vaccines, booster immunizations are recommended throughout life. Check with your health care provider about what vaccines you and your family may need.

Vaccines are safe and effective. By staying up-to-date on all recommended vaccines, individuals can protect themselves, their families, and friends from serious, life-threatening diseases.

If your child does not have health insurance, or does not have insurance that covers the cost of vaccines, ask your health care provider or local health department about the Vaccines for Children (VFC) program. This program provides no- or low-cost vaccines to eligible children, 18 and younger.

For More Information:

American Academy of Pediatrics — <http://www2.aap.org/immunization/>

MDCH: Immunization Info for Families and Providers — <http://www.michigan.gov/immunize>

For Parents: Vaccines for Your Children (CDC) — <http://www.cdc.gov/vaccines/parents/index.html>



NATIONAL HEALTH CENTER WEEK

Celebrating America's Health Centers: Powering Healthier Communities
August 5th-11th, 2012

Each year the second week in August is dedicated to celebrating the services and contributions of Community, Migrant, Homeless and Public Housing Health Centers.

While there are countless reasons to celebrate America's Health Centers, among the most important and unique is their long success in providing access to affordable, high quality, cost effective health care to medically vulnerable and underserved people throughout the United States.

You are invited this year to come join Michigan's health centers in: Celebrating America's Health Centers: Powering Healthier Communities during National Health Center Week 2012, August 5th-11th.

To locate a center event in your community visit:

<http://www.healthcenterweek.com/events.cfm?month=8&day=0&state=MI>



➔ August is Neurosurgery Outreach Month

With kids going back to school soon and nearly 110,000 student-athletes in Michigan (and around the country) ushering in the 2012-13 fall sports season on August 1st, the American Association of Neurological Surgeons (AANS) has issued an injury prevention message about football and cheerleading. The need for greater awareness about the potentially devastating consequences of head and spinal cord injuries associated with these sports led to the focus for this year's August Neurosurgery Outreach Month.

The annual incidence of football-related concussion in the United States is estimated at 300,000 and nearly 45,000 football-related head injuries are serious enough to be treated at U.S. hospital emergency rooms. While head injuries and concussions associated with football have been well publicized and subject to recent Congressional hearings, there is less public awareness about the neurological injuries associated with cheerleading, which are certainly less prevalent, but can be just as devastating. Cheerleading, which once meant cheering on athletes – has changed drastically in the last 20 years and has become a highly acrobatic sport. A number of schools at the high school and college level have limited the types of stunts that can be attempted by their cheerleaders. Rules and safety guidelines now apply to both practice and competition. These rules can be viewed at: <http://cheerrules.com/category/aacca-2/>

risk for repeated, more severe, brain injury. If athletes continue to play following a possible concussion without seeking medical care, they are putting more than just the game at risk. They are putting their health at risk. A repeat concussion that occurs before the brain recovers from the first—usually within a short period of time (hours, days, or weeks)—can slow recovery or increase the likelihood of having long-term problems. Another brain injury could result in months of rehabilitation and recovery and could mean the end of an athlete's career.



To prevent sports concussions:

- Teach your child that it's not okay to play with a concussion.
- Encourage athletes to take an active role in preventing and detecting concussion by reporting faulty equipment and any symptoms they are experiencing following a high-risk incident such as a hit or a fall.
- Ask about the coaches' perspectives on sports concussions and return to play. Understand the new protocol from the Michigan High School Athletic Association (MHSAA): any athlete who exhibits signs of a sports concussion may not return to play until cleared by a health care professional.
- Monitor your child's health throughout the season.
- Discourage attempts to "walk it off."

Concussions can occur in any sport or recreation activity. So, all coaches, parents, and athletes need to learn concussion signs and symptoms and what to do if a concussion occurs. The Centers for Disease Control and Prevention (CDC) has created free tools for youth and high school sports coaches, parents, athletes, and health care professionals that provide important information on preventing, recognizing, and responding to a concussion. Please visit www.cdc.gov/concussion/sports/index.html for more information on their "Heads Up Sports Concussion Program."

For more information about sports concussion, contact The Brain Injury Association of Michigan (BIAMI) by phone at (810) 229-5880 or (800) 444-6443; email at info@biami.org or visit the BIAMI website at: www.biami.org.

BIAMI has resources for families, coaches, teachers, school nurses and physicians regarding the symptoms, treatment, and prevention of concussions.

Sports-Related Head Injury

Although sports injuries contribute to fatalities infrequently, the leading cause of death from sports-related injuries is traumatic brain injury. Sports and recreational activities contribute to about 21 percent of all traumatic brain injuries among American children and adolescents.



Traumatic Brain Injury

A traumatic brain injury (TBI) is defined as a blow or jolt to the head, or a penetrating head injury that disrupts the normal function of the brain. TBI can result when the head suddenly and violently hits an object, or when an object pierces the skull and enters brain tissue. Symptoms of a TBI can be mild, moderate or severe, depending on the extent of damage to the brain. Mild cases may result in a brief change in mental state or consciousness, while severe cases may result in extended periods of unconsciousness, coma or even death. Sustaining a concussion weakens the brain and exposes it to greater



2012 Summer Learning Webinar Series



Join Michigan Alliance for Families as we present a free series of webinars for parents, caregivers, and educators.

All are free and run on Thursdays from noon–1 PM.

Download the flyer at:

<http://www.michiganallianceforfamilies.org/webinar/2012summerwebinars.pdf>

or register at

<http://www.michiganallianceforfamilies.org/webinar/index.htm>

Questions? Email

info@michiganallianceforfamilies.org

August 2, 2012: Advocacy and Communication with Kelly Orginski from Michigan Alliance for Families

August 9, 2012: Visual Supports Strategies with Kelly Dunlap from Statewide Autism Resources and Training Project (START)

August 16, 2012: Assistive Technology Considerations with Laura Taylor from Michigan's Integrated Technology Services (MITS)

➤ Michigan Alliance for Families Trainings: Dates/Times/Locations

Summer meeting for parents with children who have an IEP, IFSP or 504 plan and families who have concerns about their child's ability to learn and behavior issues at home and school.

- August 6, 2012 from 6:30 PM–8:30 PM at McDonald's, 4256 West Polk Road, Hart, MI 49420
- August 7, 2012 from 11:30 AM–1:00 PM at Goody's Juice & Java, 343 River Street, Manistee, MI 49660
- August 10, 2012 from 6:30 PM–8:00 PM at Goody's Juice & Java, 343 River Street, Manistee, MI 49660

For information, call Jessie Morton at (231) 843-0694 or (800) 552-4821

As always, check out our calendar of events at www.michiganallianceforfamilies.org/events to find a learning opportunity near you.

➤ Family Support Network—Support Parent Training



- August 10-12, 2012

Alpena Holiday Inn

1000 U.S. 23 Alpena, MI 49707

Lodging included, mileage and childcare reimbursed.

Onsite child care included (with prior registration). Space is limited to 25 registrants.

For more information, or to register, call: Dianna at (800) 359-3722

➤ Parent Leadership Training

Who can apply for the training?

Any parent or caregiver in Michigan who has a child aged birth to 18, who has received specialty public services in Michigan.



Parent
Leadership
In
State
Government

Is there a cost for the training? There is no cost to parents to attend.

Parents receive mileage reimbursement, a stipend (\$200) for their time, and meals during the training. Hotel may be covered based on travel distance.

How long is the training? The training is two days in length. The first day is from 1pm–8pm. The second day is from 9am–4pm. Parents must attend both days.

When & Where is it located? August 15 and 16, 2012 in Muskegon or August 21–22, 2012 in Mt. Pleasant

Is there childcare available? No, however the project provides reimbursement for childcare needed while at training (up to \$50 per day).

Have you ever wanted to use your voice to make a difference? This training teaches you how to get involved in advisory boards or committees. You will learn alongside other parents in this informative and interactive training. The goal of this training is to provide you with new knowledge and skills, as well as to help inspire and motivate you to get involved!

To apply for these trainings go to: http://www.surveymonkey.com/s/Parents_Partnering_for_Change_leadership_training_Muskegon or http://www.surveymonkey.com/s/Parents_Partnering_for_Change_Training_MTPLEASANT

A training opportunity is being scheduled for September 5–6, 2012 in Macomb County.

If you have questions please contact: Kristen Hawkins at (517) 324-7396 or Brenda Dietrich at (517) 324-8316.



➤ Michigan Family-to-Family Health Information and Education Trainings

DATES/TIMES/LOCATIONS

Accessing Health Care Coverage and Services for My Child

- October 15, 2012 from 9:00 AM – 4:30 PM at Marquette-Alger RESA, Conference Room C, 321 East Ohio Street, Marquette, MI 49855
- October 16, 2012 from 9:00 AM – 4:30 PM at Dickinson-Iron ISD Administration Building, Conference Room A, 1074 Pyle Drive, Kingsford, MI 49802
- October 18, 2012 from 9:00 AM – 4:30 PM at Mid-Michigan Regional Medical Center, Gladwin Community Education Room, 609 Quarter Street, Gladwin, MI 48624

Essential Communication Skills for IEP

- October 29, 2012 from 9:00 AM – 3:00 PM at Montcalm Area ISD, Helen Hamler Administration Building, Eastview Room, 621 New Street, Stanton, MI 48888

Everything I Need to Tell My Child About Sex

- October 8, 2012 from 9:00 AM – 3:00 PM at Eaton ISD, Conference Room C/D, 1790 E Packard Hwy., Charlotte, MI 48813

Helping Families Tell Their Stories

- October 23, 2012 from 9:00 AM – 3:00 PM at Macomb ISD, Room 206, 44001 Garfield Road, Clinton Township, MI 48038
- October 25, 2012 from 9:00 AM – 3:00 PM at Bay Arenac ISD, Academy Room, 4228 Two Mile Road, Bay City, MI 48706

Self Determination

- October 4, 2012 from 9:00 AM – 3:00 PM at Menominee County ISD, Conference Room, 1201 41st Avenue, Menominee, MI 49858
- October 16, 2012 from 9:00 AM – 3:00 PM at Huron ISD, 1299 South Thomas Road, Bad Axe, MI 48413

What Are My Rights and Responsibilities

- October 4, 2012 from 9:00 AM – 3:00 PM at Livingston ESA, 1425 West Grand River Avenue, Howell, MI 48843
- October 9, 2012 from 9:00 am – 3:00 pm at Eastern Upper Peninsula ISD, 315 Armory Place, Sault Ste. Marie, MI 49783
- October 11, 2012 from 9:00 AM – 3:00 PM at Menominee ISD, 1201 41st Avenue, Menominee, MI 49858
- October 29, 2012 from 9:00 AM – 3:00 PM at Otsego District Public Library, 219 South Farmer Street, Otsego, MI 49078

If you would like a complete 2012–13 Training Schedule, email: cook-gordonl@michigan.gov

To register for trainings, visit:

<http://www.bridges4kids.org/f2f/training.htm#1>.



Health Insurance Program (HIP)

Effective July 1, 2012, CSHCS clients who are covered by CSHCS specifically for hemophilia or cystic fibrosis and are age 18 or older and have no other insurance are required to apply for enrollment in the Health Insurance Program (HIP) of Michigan. HIP was created by the federal Affordable Care Act (ACA) for persons who are unable to acquire health insurance due to their pre-existing condition. CSHCS has determined it to be cost effective for CSHCS to pay the insurance premium payment as opposed to the entire cost of the medical care. Clients will maintain their CSHCS coverage.

HIP is full coverage insurance whereas CSHCS-only covers the special medical need for which clients are enrolled. This change will result in significantly increased health care coverage for these CSHCS clients as well as a significant cost savings to the state. Clients will maintain their CSHCS coverage as long as they are enrolled with CSHCS and as long as HIP is maintained by the federal government through the ACA. HIP enrollment will be treated the same as any other insurance in that HIP will be the first payer and CSHCS will be the payer of last resort.

Please bear in mind that people of any age and any health condition that restricts them from obtaining private health insurance coverage are eligible to voluntarily apply for HIP.

CSHCS enrollment into a Medicaid Health Plan (MHP)

Effective October 1, 2012, CSHCS clients who also have Medicaid coverage will be in the process of transitioning from fee-for-service into a Medicaid Health Plan in their area. Families/clients that only have CSHCS (no Medicaid coverage) will not be affected by this change. They will continue to receive their medical care through the fee-for-service system as usual.

Both LHDs and MHPs in the same geographic area will be contractually required to enter into an agreement with each other. The purpose of the required collaboration is to assure full care coordination that ultimately benefits the families.

For at least the first year of CSHCS/Medicaid client enrollment into the MHPs, LHD activities for CSHCS will continue to be reimbursed by CSHCS. Although both LHDs and MHPs provide care coordination and case management services, the terms have different meanings in the two environments. The MHPs are primarily medically focused whereas the LHDs have the community based and broader perspective regarding the family. One is not expected to replace the other but should be viewed as an enhancement of both sets of services for the families' use. Stay tuned for more information.